Remarks on Children with Cancer for the Hearing on Compassionate Allowances before the Commissioner of Social Security

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Diana S. Beardsley, M.D.,Ph.D.

Associate Professor of Pediatrics
Section of Pediatric Hematology and Oncology
Yale University School of Medicine
New Haven, CT

Commissioner Astrue, Panel Members, and Guests: Good afternoon. My name is Diana Schultz Beardsley and I am a pediatric hematologist/oncologist at the Yale University School of Medicine and Yale-New Haven Hospital. Parents of children with cancer face enormous medical and financial challenges as they battle these diseases. Many of our patients are eligible for disability benefits from Social Security and their families truly need these services to be able to complete a child's cancer treatment. Delays and uncertainties during the application process are common, adding further to their distress. I applaud the Commissioner's initiative on Compassionate Allowances. To provide timely and fair resources to families at a period of great need would contribute to the healing process by allowing parents to focus on a child's medical care knowing that they can maintain a home and meet the needs of other children. The fast-track approach should be applicable to childhood cancer because most institutions participate in the Children's Oncology Group and thus utilize uniform diagnostic and treatment protocols.

In the United States, one child in approximately 350 will develop cancer before 20 years of age. Fifty years ago, nearly all of these children succumbed to their disease. Cellular and molecular studies of cancers have lead to the development of effective chemotherapeutic agents, immunotherapies, and specifically targeted anti-cancer drugs. With the benefit of cooperative clinical trials, these advances, together with modern surgical and radiation modalities have made childhood cancer is one of the great success stories of modern medicine. Currently, approximately 75% of children with cancer are cured of their disease.

I will begin by describing a typical child who is diagnosed with acute lymphoblastic leukemia, the most common form of childhood cancer. The symptoms appear over a short period of time – sometimes it is the overnight onset of pain, fever, or bleeding. The diagnosis usually is made within the first two days of hospitalization and treatment is started. The parents need to deal with the diagnosis of cancer, learn about a complex treatment plan, leard to care for an indwelling venous catheter for administration of chemotherapy, prepare for frequent clinic visits, support the child through unpleasant, sometimes painful, medical procedures, and still care for the entire family. For families with limited resources who are already struggling financially this can be too much of a burden. We have excellent social work support for our pediatric oncology patients to assist families in the process of application for disability benefits, but still it may take months for a determination of eligibility to be completed.

Streamlining the clinical aspects of disability determination would allow benefits to become available when they are most needed. The volume of medical information that is often requested complicates the application process. If a request for "all medical records" is submitted to the hospital medical records department or to our pediatric oncology office, it may cause delays in response and also yield voluminous, irrelevant paperwork. Our social worker asks families to include her name on the application so that she can track a request that is made to our institution.

I was asked whether there are molecular markers that could be beneficial in identifying patients who would have a >90 per cent probability of qualifying as disabled. Cancer research is advancing rapidly, so designations will need to be reassessed regularly. That being said, I will offer one example where clinical and molecular features may be valuable to identify a subset of patients almost universally expected to meet the medical qualifications for SSA benefits: neuroblastoma. The prognosis and intensity of therapy for neuroblastoma has historically been determined by age at onset and stage of disease. It has been learned that amplification of the myc-N oncogene correlates with higher risk disease. For example, an infant under one year of age with a resectable neuroblastoma that does not have myc-N amplification can be treated with surgery alone and have an excellent prognosis. However, a child more than one year of age with a stage IV neuroblastoma that has amplification of the myc-N oncogene will require aggressive, multimodality therapy including chemotherapy, surgery, radiation, stem cell transplantation, retinoic acid treatment, and possibly immunotherapy; this child will certainly qualify to be designated as "disabled."

Compared to adult cancer, the majority of children are treated at institutions that are members of the Children's Oncology Group and a large number are enrolled on therapeutic clinical trials. This offers an opportunity for the Social Security Administration to access specific clinical and molecular qualifiers for fast tracking approval of a disability status.

I have consulted with our pediatric oncology social worker regarding typical challenges to attaining SSA benefits. In order to qualify for benefits, the guidelines require anticipated disability for at least 12 months. One measure of this is very objective - the child's income. If the guidelines are interpreted as an inability to attend school, our patients who do push themselves to go to school may not be approved – or may lose benefits later. This is particularly problematic. Most of these children will be cured. We encourage them to maintain both social interactions and also their school progress. This may mean attending school for an hour or two a day or a couple of days a week when they are not receiving chemotherapy. This can be "therapeutic" for the child, but it shouldn't be interpreted as an indication that the child is no longer disabled.

One medical condition that nearly always should qualify the patient for a designation as disabled is a relapse of the cancer. Is it possible to maintain a record of a patient who has previously completed an application and either been deemed to be medically ineligible or approved but completed therapy and stopped receiving benefits? A streamlined application process might allow such individuals to be promptly approved by simply confirming the relapse of cancer.

Currently, approximately 75% of children with cancer are cured of their disease. ("Cures" are typically defined as remaining in continuous remission for a period of five years.) There are currently approximately 270,000 survivors of childhood cancer in the Unites States, and that number will increase significantly in the future. Remaining free from cancer is not the only challenge that our patients and their families face. They do not automatically return to being normal healthy individuals at the completion of therapy. The study of late effects of childhood cancer treatment is a rapidly growing area of clinical investigation in pediatric oncology. We are learning that two-thirds of children treated for cancer develop a complication of the therapy and that half of this group have a serious medical problem such as congestive heart disease, mental impairment, or lung damage. I am pleased to know that cancer survivorship issues are represented on the Panel.